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ABSTRACT

"Managed care" is a term used to describe health care plans in which a primary provider typically monitors all of a patient's care within a specific network of providers. It differs from the traditional fee-for-service model in that patients often are expected to pay extra if they want to see out-of-network providers. Additionally, managed care plans may have their own decision makers, who have the power to override a physician's decisions. Families of young children who are eligible for early intervention and preschool services need clear information about how to ensure that their children receive the best possible health care under managed care plans. This article addresses issues for parents to think about and questions to ask. It provides contact information on important people for parents to call for assistance, and it defines common terminology used regarding this issue. Both the strengths and weaknesses of managed care are addressed. (SG)

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EARLY CHILDHOOD BULLETIN

"WHAT PARENTS NEED TO KNOW ABOUT MANAGED CARE"

By

NORA WELLS

DECEMBER

1997

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EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NEC*TAS

December 1997

"What Parents Need to Know About Managed Care"

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Managed care is a term used to describe new ways of structuring and paying for health care. There are many variations in managed care plans, with new options emerging all the time. Families in both Medicaid and employer-based plans are more and more frequently faced with joining managed care plans. The movement into managed care is sweeping the county and having a profound influence both on how health care is delivered and on what health care services are received. Families are anxious to understand how these changes will affect the health care their children, as well as all members in the family, receive. Families of very young children with special needs, those eligible for early intervention and preschool services, have a particular need for clear information about managed care and how to effectively ensure that their child and family receive the best health care. The philosophy of early intervention provides a framework for comprehensive family-centered services for children. Families will be important players in ensuring that managed care delivers the services children and families need.

What is managed care?

The term "managed care" describes a payment process for health care that differs from the old fee-for-service system in which medical care was paid for each time it occurred, and patients had free choice of the providers they would use. In managed care plans patients usually must chose from a limited network of providers, as a primary provider monitors all of a patient's care and refers patients to specialist care (this provider is often referred to as a "gatekeeper"). Some managed care plans provide all of the patient's care within a specific network of providers, while other managed care plans allow enrollees to use out-of-network providers if the enrolee is willing to pay a higher share of the cost. The managed care plan may have its own decision makers who oversee the cost of patient care and may override a physician's decision. The way in which a managed care plan finances health care can differ in important ways. Managed care plans may have all or most of their providers on staff, or they may negotiate contracts directly with networks or groups of health providers such as doctors, hospitals, therapists, and equipment dealers to provide services to their enrollees at a specific rate. Payment may be through several models; one set fee for all of the services a patient may need, regardless of how many services the patient uses (a full captitation model), or a capitation model only for primary care, or a more open model where care is paid for as it occurs but at a pre-set rate. There may be incentives given to providers to keep the costs of their patients' care low. Many managed care plans contract with separate managed behavioral care plans for mental health services. It is helpful for parents to know how the specific plan they are dealing with is financed so that they know whom to speak with about a given issue. Parents probably have to ask to find out.

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Choosing a plan

Most of us are given a choice of managed care plans, either from our employer or from Medicaid. Your decisions can make the difference between receiving quality health care for your child or finding it difficult or impossible to receive the services and reach the providers your child needs. Where do you start? Here are some tips:

- Think about the kind of care your child needs, from routine to specialty care, and ask your child's doctors, nurses and therapists, as well as other families with similar needs, what kinds of services, tests, equipment, supplies, and other medical goods they think your child will need.

- Make a list of what is most important for your child. Access to certain hospitals? Referrals to pediatric specialists? Certain medicines? What else?

- Ask for written materials about the plans you are considering. If you have difficulty understanding the information you are given, contact the Managed Care Organization (MCO)'s customer representative, your Medicaid case manager, your employee benefits manager, or a parent or child advocacy organization.

- Attend presentations made by the different MCOs and ask questions.

- Use your list to decide which plans address your child's most important health care needs.

- Keep in mind that what works best for your child with special health care needs might not work for the rest of your family (if everyone in the family is to be part of the same MCO).

- Based on the facts you gather, try to make a good decision. But, just in case things do not work out, find out the rules and deadlines for switching plans.

QUESTIONS TO ASK...

...ABOUT DOCTORS AND OTHER PROVIDERS

- Is my child's current primary care provider (PCP) now in this MCO?
- Are any/all of my child's doctors listed as providers in this plan?
- If he/she is not in this MCO, can my child's provider become a provider for this MCO?
- Can a pediatric specialist be my child's PCP?
- Are there pediatric primary care and specialty care providers in the MCO who know about children like mine? How can I find that out?
- Are providers paid extra for the time it takes to take care of children with special health needs?
- Can I change primary providers if I'm not satisfied? How? How often?
- Can I use doctors and other health care providers not in this MCO? What steps must I take to go outside the MCO? What will it cost me?
- Is the doctor I want accepting new patients?
- Can I use the same equipment dealers, home-nursing agencies, pharmacies, therapists and counselors who serve my child now?
- If I must change some providers, how do I make sure that the services and equipment my child needs don't stop during the change-over?

...ABOUT BENEFITS AND COVERED SERVICES

- Does the MCO have a special program for children with special health needs? How is eligibility for this program decided?
- Are there any limits on the amounts of services my child can receive, such as therapies, home care, equipment? If there are limits, can exceptions be made? Who decides the exceptions? Will there be a cost to me?
- What mental health services are covered? Who are the providers? How much treatment is covered?
- Looking at the list of services my child needs, are any of them excluded from this MCO?
- If I find providers, supplies, equipment, or medications that are more convenient and cost effective than those in the network, can I use them? Whose permission must I ask? What will it cost me?
- Can providers in the plan use new technology or unusual treatments that will benefit my child? Or are they excluded?
- Are case management services provided? Automatically? Or by request? How does the MCO define "case management"?

QUESTIONS TO ASK...

...ABOUT ACCESS TO SPECIALISTS

- Is care from my child's specialist/s paid for?
- Who makes referrals to specialists? The PCP? Another specialist? Benefits manager? Case manager? How long does this referral take?
- Does the plan include pediatric specialists in the areas of my child's special needs; i.e., neurologists, orthopedic doctors, psychiatrists, psychologists, radiologists (X-rays, MRIs, etc.), orthotics technicians, occupational, physical, and speech therapists?
- Can one referral cover a number of specialist visits?
- Are services at specialty centers (like a Spina Bifida Center) paid for?
- Are the specialist(s) my child needs taking new patients?
- Can my child see a specialist or receive services without a referral from his PCP?
- Will the MCO require my child to be in an institution in order to receive certain specialty services?

...ABOUT PRESCRIPTION MEDICATIONS

- Are my child's medications on the list of approved medications?
- Is a non-generic medicine covered if it is the best choice for my child?
- Is there pressure to prescribe generics instead of more expensive medicines?
- Must I buy prescriptions from a particular drug store or pharmacy? Is it convenient for my family?
- Is there a co-payment for prescriptions?
- Must I use mail-order?

...ABOUT HOSPITALS

- Which hospitals are covered in the plan?
- Can my child use the nearest major pediatric center, even if it is not listed by the MCO?
- How can I find out about the quality of the pediatric units at listed hospitals?
- What hospital services are covered by the plan?
- What hospital services require prior approval?
- How many days of inpatient care are covered each year? Is the type or amount of inpatient coverage different for mental health?

Managing your managed care plan

Remember, managed care is a business, and you are the customer! Most MCOs want their customers satisfied and healthy. Because many MCOs are new at providing health care to children with special health needs, parents can educate them about our children and what they need to stay healthy and avoid more serious health problems. MCOs are also interested in saving money, so it's important for them to understand that quality care for our children with special health care needs can also be cost effective.

KNOW ABOUT...

Primary Care Providers (PCP): In most managed care plans, the PCP can be a physician, a nurse, or a nurse practitioner. Often called a "gatekeeper," the PCP makes decisions about care and referrals to other health providers. If you and your child like your PCP, but must change plans, ask him or her to join your new plan. Or, ask the plan to include your child's PCP in their network. If starting with a new PCP, arrange for a first visit, and discuss your child's health needs and the PCP's experience with children like yours. If the PCP does not work out, find out how you can change PCPs within a plan. *Note: In some Medicaid programs a Primary Care Case Manager (PCCM) performs a PCP's functions.*

Prior Approval: Other than appointments with your child's PCP, you will probably need a referral beforehand for most services. Look for other requirements, such as calling the plan within 24 hours if your child has used the emergency room or been admitted to the hospital. Make sure you understand what must be done for these services to be approved.

Out-of-Plan Services: If you think an out-of-network provider or a service not described in the plan's coverage is essential for your child, your doctor will need to explain why the care is medically necessary.

Medically Necessary: In a managed care system, health care must be determined to be medically necessary. Make sure your primary care provider or specialist knows what services your child has received in the past and what service descriptions lead an MCO to consider services medically necessary and therefore covered. Ask about clinical standards that are the basis for medical necessity decisions. Warning! Some words frequently result in denials, such as experimental, cosmetic, habilitative, custodial, nutritional, respite, for example.

Service Limits: Be sure to discuss with your PCP what kinds of care or services have restrictions in the amount of or cost allowed. Your child may require an exception to policy to allow for these services.

Your Health Policy/Plan: Your child's health plan, whether financed by Medicaid or your employer, is based on a legal document called a contract or policy. The policy explains the benefits your child is entitled to and the rules of the plan. Make sure you have the latest version of your child's policy and that you understand it. If your plan comes through your employer, talk to your company's benefits manager. Every company has a plan they develop with the insurance company or MCO; these are negotiated and changed regularly.

Records: Important records or documents include: your child's health policy and identification numbers; your child's health plan ID card; telephone numbers of contact people; copies of all letters from the MCO, doctors, case managers, etc.; notes of phone conversations; bills and notes from all visits and services that your child has had. Keep these records in one place at home. Every time you talk to someone at the MCO, write down the date and time and the person's name, and what they told you. If something they say seems important, ask them to put it in writing and send it to you. Keep these records!

QUESTIONS TO ASK...

...ABOUT COST

- What are the plan's premium charges- to my employer, to me?
- What are the deductibles? Co-payments?
- Are there services that my child requires that will always include an extra payment? What are they?
- Is there an annual limit on the amount of co-payments and deductibles I pay?

...ABOUT WHO MAKES DECISIONS

- Who makes decisions about the care of my child: Me? PCP? Specialist? Benefits Manager? Case Manager? All of us
- Can I find out the clinical standards used in making a decision?
- Are decisions made by trained medical providers who actually treat my child, or are they made by someone's reading my child's written record? What qualifies this person to make these decisions?
- What can I do if I do not agree with a decision? Is there a formal process? An informal process?
- How long does it take to change a decision? What if it is an emergency?

...ABOUT EMERGENCY CARE

- How does the plan define "emergency"?
- Is ambulance service always covered?
- Is there an explanation of what to do when my child is in an emergency situation? What would not be considered an emergency?
- Am I limited to certain emergency rooms? Where are they?
- How much will it cost me when my child uses an emergency room?

QUESTIONS TO ASK...

...ABOUT URGENT CARE

- How does the MCO define "urgent care"?
- What happens if my child needs urgent care when far away from home or in another state?
- What procedures must I follow for unscheduled and after-hours care that is urgent, but not an emergency?

...ABOUT MEDICAL EQUIPMENT, HOME HEALTH, TRANSPORTATION

- What kinds of medical equipment are paid for?
- Which pediatric equipment vendors are listed?
- Looking at my child's list of needed services, does this MCO pay for all the durable and non-durable equipment and supplies we need?
- Does the MCO pay for equipment repairs and replacements? Is there a limit on how much and how often?
- Are home-health services paid for? Which agencies are used?
- Is transportation to clinics, hospitals, and appointments paid for?
- Are there time or cost limits for these kinds of services?
- Are there co-payments?
- How do we find and use these services?

...ABOUT QUALITY AND CUSTOMER SATISFACTION

- May I see reports that rate the MCO's quality of care and consumer satisfaction? Can I also see reports of complaints and appeals?
- Is there an advisory committee for family feedback to the plan?
- How do I make a complaint if I am not satisfied with the MCO's services?
- Do I make a complaint to the MCO? To my employer's plan? To Medicaid? To the State Insurance Commission? To an ombudsman?
- What do I do when a service is denied or a referral not made? Can I appeal that decision? How?

Billing Records: Always check the bills and the "explanation of benefit" forms you receive to make sure they are accurate and that the service really was provided. Keep copies.

Complaints: First, find out what the complaint and/or grievance procedure is for your plan. In some states, you begin the process with the MCO; in others, it's the Medicaid agency, Ombudsman, or Insurance Commission. If you are unhappy with the care your child has received, talk to your PCP and any other involved provider immediately. If you are not satisfied with that discussion, call your main contact at the MCO. Have all records in front of you. Explain your complaint and ask for an explanation in writing. Try to resolve the complaint early. But be prepared to go through a formal complaint process.

Denials: If services have been denied, limited, or delayed, request an explanation in writing from your PCP. Sometimes, by sheer determination, you may be able to get the MCO to reconsider a decision. All organizations make exceptions, so ask for one.

Appeals: If you are still not able to resolve the denial, find out about the plan's formal process for appealing a decision. The written materials from your child's plan should give you information on how to appeal a decision. The appeals process is different from state to state, and may even differ from plan to plan, but some things are the same. If your coverage is through an employer, check with the company's personnel office or human resources department about how to file an appeal. If your child's managed care coverage is through Medicaid, the Medicaid agency will have information about how to appeal. If, after an appeal, you are still not satisfied, you can file a formal complaint either with the Medicaid agency or with the Commissioner of Insurance for your state. Finally, if nothing else works, obtain legal assistance. There are free legal services in every state for families who meet income guidelines. Many

of these offices will also discuss issues with families over the phone, even if they are over income guidelines. Sometimes families who feel their child has been denied care unjustly turn to the press to highlight the situation.

*Remember...*Your expertise about your child and your knowledge of how your managed care plan works are powerful tools that help to make sure your child receives the right kinds of health care.

Important People and Phone Numbers: The following people can be your partners in assuring quality health care for your child:

- Your child's PCP. Build a strong and positive relationship with her/him.
- A case manager, if the MCO assigns one. This is the main MCO contact to talk to about your child's special needs.
- The benefits manager in charge of health benefits at your work or a benefits manager or case manager within the Medicaid agency.
- A toll-free hotline or ombusdman program.
- The person in the plan who deals with your employer or the Medicaid agency.
- National Committee for Quality Assurance (NCQA) will send a free list of certified managed care plans and those under review or denied certification. Call 202-955-3500.
- Health Care Financing Administration (HCFA). HCFA can tell you whether a given plan is federally qualified. Call 410-786-4287.

Managed care and family participation

As states begin to enroll Medicaid eligible families of children with special needs in managed care, there will be many opportunities for families to get involved in important ways. To join these discussions, you will want to know some of the following terms:

Carve Outs: If you get involved in state-level discussions about managed care, you may soon hear this term. One way this term is used refers to a carve-out model that takes groups of services, such as mental health services or early intervention services, and separates them from the main managed care benefit package, setting up a separate system for how they will be provided and paid for. More than half of the states are presently carving out early intervention services from Medicaid managed care plans. Many managed care plans, both Medicaid and employer based, have taken this approach with mental health services. Another kind of carve-out separates specific groups of people, such as children with special health needs, or the disabled, and exempts them from a requirement to choose a managed care plan through Medicaid, while other Medicaid populations are being required to enter managed care. This may only work in the short run, however, and may not answer the question of how to meet these people's needs within managed care.

Contracts: As Medicaid agencies begin to require their beneficiaries to enroll in managed care plans, contracts must be written between the states and MCOs. These contracts will be public; overseeing them is a key area for family participation. Important areas for families to look at and comment on are included on the list following this section. Some states are requiring MCOs to set up an advocacy system, such as an exceptional needs care coordinator, either within the MCO itself or outside the organization to help people with special needs. Your state Interagency Coordinating Council may have a committee looking at many aspects of Medicaid managed care including the state contract. You may be able to have an impact on this process through the state Medicaid Advisory Board, which by law must include consumers.

Early Intervention Services and State Protections: States are required to provide all children eligible for Medicaid with a comprehensive package of benefits (Early Periodic Screeening Diagnosis and Treatment EPSDT). But as they contract with managed care

organizations, the MCOs may not know what is included in this comprehensive set of benefits.

Likewise, a number of states require health plans within the state to provide early intervention services, but an MCO new to the state may not be aware of this requirement. Families can help ensure that MCOs are informed about and are held responsible for these requirements.

Issues to Look at

- *Contractor qualifications:* both of the MCO and the providers in its network
- *Marketing:* What kinds of information will be given to families?
- *Enrollment:* How many families will be involved?
- *Access to care:* Where the providers are located?
- *Selection of PCPs:* What PCPs are in the plan? Do they have pediatric training?
- *Availability of pediatric specialty providers:* What providers are in the plan? Do they have pediatric training?
- *Data and reporting:* What will the MCO need to report on?

Roles for Families in Monitoring and Improving Managed Care Systems in Their State: One benefit of managed care systems is their emphasis on measuring quality by asking consumers how they rate the care they receive. It is important for families of children with special health care needs to be sure that families are asked the kinds of questions that reflect quality care for their children. As a family advocate, try to get involved with how your state is monitoring managed care. What is the Medicaid agency requiring MCOs that are enrolling children with special needs to report? Are there questions specifically on pediatric specialty services, amounts of therapy services provided, choice of providers? Ask to see what kinds of data MCOs are collecting. Are they useful? What will be done with the data? Is it ethical?

Integration of Services - Systems That Work Together: The movement into managed care provides a new opportunity for children to receive more coordinated care, but this may not happen without strong support from families. Ask that MCOs be required to work with early intervention, preschool programs and public school systems and that families are always at the table as they make plans and policies.

Family Voices Survey

This national survey of family experiences with health coverage, funded by the Packard Foundation, the Butler Foundation and the Maternal and Child Health Bureau will ask over 6000 families to report on how their children with special needs are faring in both fee for service and managed care plans, through Medicaid and employer based plans. Results are expected in the Fall of 1998. Contact Nora Wells at (617) 482-2915 x123 for more information.

*Parts of this article have been drawn from the Family Voices Managed Care Booklet, from a NEC*TAS ICC Parent teleconference on managed care in 1996 and from information presented at a 1997 NEC*TAS Managed Care Meeting.*

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Announcement of NEC*TAS Sponsored Meeting

NEC*TAS has announced the meeting of Part H/C Coordinators and the 619 Coordinators to be held in Washington DC on **March 22-27, 1998.**

On Sunday and Monday sessions will focus on Part C/Early Intervention. Tuesday and Wednesday there will be sessions of general interest, and on Thursday and Friday the focus will be on 619 and preschool services. Details of the agenda and registration information will be available in January. The Federal Interagency Coordinating Council is scheduled to meet Wednesday, March 26 at 1:00 PM.

Parents who are interested in attending any of these sessions should contact the Part H or 619 Coordinator in their state to discuss the possibility of attending and to receive information about logistical and registration materials.